University of Sheffield

MA in Social Work

Dissertation (SCS 6140)

Personalised support systems and disabled adults: An analysis of the financial barriers to independent living

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Appendix 2

DEPARTMENT OF SOCIOLOGICAL STUDIES SHEFFIELD UNIVERSITY

Research Ethics Review Checklist

This checklist should be used for all research projects. It should be accompanied by a research proposal.

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Title of Dissertation: Personalised support systems and disabled adults: An analysis			
of the financial barriers to independent living			

Research checklist

(Please tick)	YES	NO
 Does the study involve participants who are particularly vulnerable or unable to give informed consent? 		V
2. Will it be necessary for participants to take part in the study without their knowledge/consent at the time?		\checkmark
3. Will the study involve discussion of topics, which the participants might find sensitive (e.g. sexual activity, own drug use)?		\checkmark
4. Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond risks encountered in normal life?		N
5. Will the study involve prolonged or repetitive testing?		\checkmark
6. Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?		V
7. Will the study involve recruitment of patients or staff through the NHS? If it does you are alerted to the requirements for ethical approval of NHS related research activities.		V
8. Does your research involve participants under the age of 18?		\checkmark

IF YOU HAVE ANSWERED YES TO ANY OF THE ABOVE QUESTIONS, IN THE BOX BELOW, PLEASE NOTE THE NUMBER AND PROVIDE FURTHER INFORMATION ABOUT HOW YOU WILL MANAGE THIS ISSUE – CONTINUING ON THE BACK IF NECESSARY

When reviewing the answers to these questions the ethics committee will be concerned primarily with whether you have mounted an adequate defence of how you intend to handle any ethical issue that arise.

Please note that it is your responsibility to follow the University's Code of Practice on Research Ethics <u>http://www.shef.ac.uk/r/researchoffice/RO/ethics_policy.pdf</u> and the **Code of Ethics for social work and social care research** (see Appendix 3). Data should also be handled in a manner compliant with the Data Protection Act.

Please sign below to say that you have read the University Code of Practice and the Code of Ethics for social work and social care research, and that the information you have provided here is accurate. It is the responsibility of the student to ensure that the research is carried out in an ethical way, and it is the responsibility of the student to inform the supervisor of any changes that occur in the research process. The supervisor's signature indicates that the supervisor is satisfied with the student's response on this form.

STUDENT

SUPERVISOR

DATE

University of Sheffield	NAME: Christopher Renshaw	
	YEAR OF SUBMISSION: 2007	
ABSTŘÁCT	TITLE	
ADSTRACT	Personalised support systems and	
MASTER OF ARTS SOCIAL WORK	disabled adults: An analysis of the financial barriers to independent livi	
Abstract: Personalised support systems - care management, direct payments		

Abstract: Personalised support systems – care management, direct payments and individual budgets – are designed to meet the needs of individual service users. In recent years, government policy (PMSU, 2005) and legislation (DH, 2005; DH, 2006) has promoted the use of these systems with a growing emphasis being placed on direct payments and individual budgets. Whilst this development is encouraging, the government has failed to invest in the social care system and expects, instead, that social services departments will make "efficiency savings" and use the savings to develop personalised support systems. Many disabled people claim that direct payments and individual budgets enable them to live independently in the community. While there is much evidence to support this, the extent to which independent living is achievable in the current economic and financial climate is questionable.

The aim of this dissertation was to gain a greater understanding about the financial barriers to independent living and to find out how the social work role in relation to funding impacts upon social worker-service user relationships. In order to do that, an extensive review was conducted of relevant literature. The findings suggest that financial barriers hinder the ability of personalised support systems to enable disabled adults to live independently, particularly in relation to rising eligibility criteria, since many disabled adults only receive support if their needs are "substantial" or "critical". The findings also suggest that the role of social work in relation to funding has a negative impact on social worker-service user relationships.

Key Words: Personalised support systems; financial barriers; independent living, cost efficiency; social work role.

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Chapter One

Introduction

In recent years, social care policy and practice has become more "personalised" (PMSU, 2005; DH, 2005; DH, 2006). This means that services are increasingly being designed around the needs of individuals rather than communities or groups of service users. The Social Care Institute for Excellence (SCIE) uses the following definitions for personalised support systems:

- "Care management the development of individual care plans, based on detailed assessments by budget-holding care managers, taking full account of the service users' wishes and needs.
- Direct payments where people, after assessment, are given money to pay for their own social care, along lines proposed by them and discussed with their care manager.
- Individual budgets a system which involves streamlined assessment across a number of support funding streams, resulting in the transparent allocation of resources to an individual, in cash or in kind, to be spent in ways which suit them" (SCIE, 2007, p. 3).

Recent government policy (PMSU, 2005) and legislation (DH, 2005; DH, 2006) acknowledges that traditional community care services have failed to meet the needs of disabled people and has established that direct payments and individual budgets are to be central components of social care provision in future. What the government fails to either explicitly state or acknowledge is that, due to economic pressures, it has not been able to provide social workers with sufficient financial

resources to promote independent living principles within the social work environment (e.g. Priestley, 1999; Barnes and Mercer, 2006; CSCI, 2006; LGA, 2006; Wanless, 2006; Beresford, 2007; Ellis, 2007, Holloway and Lymberry, 2007).

The Social Model of Disability

Social policy and legislation often use medical or individual definitions of impairment and disability. The International Classification of Impairments, Disabilities and Handicaps (ICIDH), or similar definitions, have been used extensively by the government and professionals working with disabled people. The ICIDH defines impairment, disability and handicap as follows:

- *"Impairment*: Any loss or abnormality of psychological, physiological or anatomical structure or function" (p.27).
- "*Disability*: Any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within a range considered normal for a human being" (p.28).
- *"Handicap:* A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual" (p.29) (WHO, 1980, cited by Barnes and Mercer, 2006,

p. 20).

A causal link is, therefore, made between impairment, disability and handicap. In the definition of "disability", reference is made to "normal" human performance or

activity. The implication here is that disabled people are not "normal" human beings and this definition is, therefore, highly discriminatory. That disabled people are not considered to be normal is obvious if you consider, for example, their historical segregation from society (Hunt, 1966; Barnes, 1991a; Priestley, 1999; Oliver and Sapey, 2006) or the way in which professionals are given powers to assess disabled people's needs and plan their "care" (DH et al., 1990; DH et al., 1991b). The service response to impairment and disability is, therefore, to rehabilitate people so that they are able to cope with their situation and not to address the social and environmental barriers to disabled people's exclusion from society (Barnes, 1991a; Oliver and Sapey, 2006).

In 1976, the Union of Physically Impaired against Segregation (UPIAS) argued that "it is society which disables physically impaired people" (UPIAS, 1976, p. 14) and defined impairment and disability as follows:

- *"Impairment*: Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body".
- Disability: The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS, 1976, pp. 3-4).

This broke the causal link between impairment, disability and handicap. Whilst their definition of impairment is similar to the ICIDH definition of impairment,

disability is defined very differently, with an emphasis on societal exclusion and discrimination. This definition was later extended to include all disabled people. This was a defining moment in the history of the Disabled People's movement and "prompted Mike Oliver to coin the phrase the "social model of disability" to refer to:

"Nothing more or less fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations upon certain groups or categories of people" (Oliver, 1983, p. 23, cited by Barnes and Mercer, 2006, p. 36).

Aims and objectives

It is fascinating when reading about personalised support systems and disabled people that so little mention is made regarding the financial barriers to independent living and their impact on social work with disabled people. Except for Zarb and Nadash's (1994) report *Cashing in on independence: Comparing the costs and benefits of cash and services,* very little attention has been paid to the subject at all. More recently, in attempting to rectify this problem, Hurstfield et al. (2007) published a report called *The cost and benefits of independent living.* The aim of this dissertation is to examine more carefully whether financial barriers have an impact both on the ability of personalised support systems to give disabled people more choice and control over their lives and on the social work role in relation to funding and whether this has an impact on social worker-

service user relationships. In order to meet those aims, an extensive review of the literature was conducted with the most relevant findings being used to answer the main questions posed by this dissertation.

Since the Independent Living Movement (ILM) and Disabled People's Movement have been heavily involved in bringing about change in the social care system (Priestley, 1999; Glasby and Littlechild, 2002; Leece and Bornat, 2006; Barnes and Mercer, 2006), the author has decided to use a social model analysis during this dissertation as it is felt that this offers possibilities for critical analysis of the financial barriers to independent living.

Dissertation outline

The author acknowledges that the concept of personalised support may be new to some readers. In chapter two, therefore, a concise analysis will be made of the ideological, political, policy and legislative changes which inspired the idea of personalised support. The three main forms of personalised support – care management, direct payments, individual budgets – will then be introduced and a brief synopsis of developments in those areas will be made. Throughout the dissertation, the views of disabled people will be taken into consideration because they have been at the forefront of campaigning for change in relation to the social care system.

One of the major barriers to independent living is the lack of political will to invest in social work with disabled people. Over the last ten years, funding for social care has been increasing gradually but, at the same time, eligibility criteria for community care services has also been rising. The outcome is that fewer people are receiving direct social work input and that those who benefit from such support have the most complex needs (CSCI, 2006). Those with "low" or "moderate" (DH, 2002, pp. 4-5) needs have been receiving less and less input from social workers (LGA, 2006). In chapter three, therefore, we will examine the impact of financial barriers on independent living opportunities for disabled people.

The introduction of personalised support schemes in the UK has impacted greatly on the nature of social work and the roles and tasks social workers are expected to carry out. In chapter four, therefore, attention will be given to the social work role, particularly in relation to funding, because this has affected the relationship which social workers have with disabled people. Several themes will be covered including social work assessment, financial assessment and benefits, and service commissioning.

Finally, the dissertation concludes by arguing that personalised support systems such as direct payments and individual budgets give disabled people more choice and control over their lives compared to traditional services but that this is hindered by the government's desire to limit public expenditure and to promote

the principle of cost effectiveness in social care. It is also argued that the social work role in relation to funding has impacted negatively on social workers relationships with disabled people.

Chapter Two

Personalised support systems: History, ideology, social policy and legislation

The Poor Law and institutionalisation

Glasby and Littlechild (2002) and Barnes and Mercer (2006) argue that the beginnings of cash-for-care policy can be traced back to the Poor Law Act of 1601. This "provided an enduring, decentralised basis for distributing relief payments to those in extreme poverty and unable to provide for themselves" (Barnes and Mercer, 2006, p. 10), including disabled people. Between the 16th Century and 20th Century, with the industrial revolution and the growth of a capitalist economy, a distinction was made between the ""deserving" (or unemployable individuals including sick and infirm people) and "undeserving" (or "able-bodied") poor deemed capable of employment..." (Barnes and Mercer, 2006, p. 10). The Charity Organisation Society (COS), which Glasby and Littlechild (2002) argue heralds the beginning of social work as a profession, was set up in 1869. Leading COS figures, they say, believed that "poverty was caused by individual and moral failings - by fecklessness and thriftlessness" (Glasby and Littlechild, 2002, p. 5). COS workers were responsible for "assessing whether an individual was worthy or unworthy of assistance" (Glasby and Littlechild, 2002, p. 5). The "deserving" could get access to charity whereas the "undeserving" could not and, instead, had to work in the workhouses, which were "brutal and dehumanising" (Glasby and Littlechild, 2002, p. 6).

Barnes and Mercer (2006) suggest that the capitalist "pursuit of economic rationality and profitability" with an "increasingly market-oriented economy" made work more challenging for disabled people. At the time this:

"exacerbated the representation of people with impairments as a "social problem" – not capable of making a proper economic contribution and a "burden" on their family and local community. Their perceived "unruly" character and "degenerative" character legitimised a range of institutional solutions – prisons, workhouses and asylums (Barnes and Mercer, 2006, p. 11).

By the end of the 19th century, the institutionalisation of disabled people was perceived to be normal and acceptable and the number of asylums rose substantially. The institutionalisation of disabled people continued well into the twentieth century (Table 6.3 in Barnes, 1991b, p. 6, adapted from Fig. 5 in Gray et al., 1988) when there were 422,000 disabled people in residential care and, although significant progress has been made, even today 346,000 disabled people are still in residential care (NHS, 2007, p. v).

Welfare benefits and community Support

Remnants of the Poor Law were still evident in the 1920s and 1930s, with people in need of state assistance "only receiving support if they were extremely impoverished and if no other source of support was available" (Glasby and Littlechild, 2002, p. 6). In 1948, the Poor Law was abolished. In its place, the National Assistance Board was set up to administer social security benefits and

the National Assistance Act (NAA) 1948 enabled local authorities to "provide welfare services for older and disabled people" (Glasby and Littlechild, 2002, p. 7). Section 29 (6) of the NAA 1948 prohibited local authorities from making payments to service users (Clements, 2004, p. 560). This effectively ended the identification of social work with the Poor Law and poverty issues. The introduction of direct payments legislation in 1996, permitting local authorities to make direct payments to service users, "must be seen as a radical departure from current social work practice, re-establishing the professions links to its pre-1948 history" (Glasby and Littlechild, 2002, p. 8).

Oliver and Sapey (2006) argue that "the current role of social services departments emanate from the Seebohm Report" (p. 8). The Local Authority Social Services Act (LASSA) 1970 established social services departments to take these recommendations forward. In 1970, the Chronically Sick and Disabled Persons Act (CSDPA) took forward Seebohm's recommendations about providing services to disabled people. Section One of the CSDPA 1970 placed a duty on local authorities to find out how many people in their area could benefit from the Act and to provide information about their services to the general public. Section Two of the Act permits local authorities to provide "practical assistance" for disabled people in their homes as well as support to enable disabled people to live out their lives in the community (Clements, 2004, p. 563).

Although these services were, potentially, already available under the NAA 1948, social services departments had not made, for financial and other reasons, good use of these provisions. It was hoped that this Act would lead to a better mix of residential and community services for disabled people. Having said that, Oliver and Sapey (2006) also argue that "this Act was passed at a time of organizational upheaval when there were also the competing demands of other client groups, notably children" and that "it also suffered from being inadequately resourced" (p. 8). Consequently, although this seemed to be a very positive Act for disabled people, organisational change and resource barriers meant that it was poorly implemented.

De-institutionalisation

At the same time as these changes were taking place, the government was under increasing pressure from disabled people and the general public about the standards of support for disabled people living in institutions. As Barnes and Mercer (2006) note, "public criticism of large-scale institutions reached a peak in Britain in the 1960s and 1970s, fanned by a series of scandals in long-stay "mental handicap" and "psychiatric hospitals"" (p. 17). These institutions were criticised for the imbalance of power between staff and residents, as well as the lack of "autonomy", "respect", and "choice" (Barnes and Mercer, 2006, p. 17) accorded to disabled residents. Miller and Gwynne (1972) described such an existence as "a social death sentence" (cited by Barnes and Mercer, 2006, p. 17). Government initiatives, such as the "10-year Hospital Plan in 1962" (Barnes

and Mercer, 2006, p. 18), henceforth sought to dramatically reduce the number of disabled people living in institutions with the aim of "eliminating it completely by the end of the century" (Barnes and Mercer, 2006, p. 18). *Modernising Social Services* (DH, 1998), published in 1998, identified that this aim had not been met.

Disability activism and independent living

It is widely recognised that disability activism and the emergence of the Independent Living Movement in the UK are linked to disabled people's desire to live their own lives, to have "choice and control" over their support and to be recognised as citizens with rights and responsibilities (Barnes, 1991a; Morris, 1993; Campbell and Oliver, 1996; Priestley, 1999; Glasby and Littlechild, 2002; Barnes, 2005; Morris, 2005; Barnes and Mercer, 2006). In Britain, this was "largely centred on small groups of disabled people living in residential institutions" (Barnes and Mercer, 2006, p. 33) who wanted to live in their own accommodation.

Disabled people have re-defined independent living to mean "all disabled people having the same choice, control and freedom as any other citizen – at home, at work and as members of the community" (Barnes and Mercer, 2006, p. 33). Brisenden (1989) says that "independence is created by having assistance when and how one requires it" (Brisenden, 1989, p. 9, cited by Barnes and Mercer, 2006, p. 33). Inspired by the success of disabled students at the University of California in Berkeley in establishing firstly their own support services whilst at

University followed by the first Centre for Independent Living (CIL) in 1972, British disability activists sought to establish similar support services in the UK. As a result, two CILs were established in Hampshire and Derbyshire during the early 1980s. In Derbyshire, Derbyshire Coalition of Disabled People (DCDP) developed its "philosophy of integrated living...around seven core areas of need – information, counselling, housing, technical aids, personal assistance, transport and access" (Priestley, 1999, p. 71).

Before the Independent Living Fund was established in 1988, many disabled people set up their own services through "indirect payments" schemes. Although the legality of some of these schemes was at times questioned (Glasby and Littlechild, 2002, p. 20), these schemes enabled disabled people to have more choice and control over the services they received. A variety of different indirect payments schemes emerged. These ranged from Project 81, a partnership whereby disabled people living in residential accommodation persuaded their local authority to give them money, through their residential provider, to live independently (Zarb and Nadash, 1994, pp. 5-6; Glasby and Littlechild, 2002, p. 20), to money provided to individual via Centres for Independent Living or voluntary organisations, and even to a "non-charitable Trust for the benefit of an individual...(whereby) the local authority hands an agreed sum of money over each year to a Trust" (Morris, 1995, cited by Glasby and Littlechild, 2002, p. 21).

Community care and care management

Priestley (1999) argues that the change from institutional to community care provision was "accelerated by two factors":

"On a structural level, fiscal crisis and spiralling public sector borrowing heightened the economic imperative for greater efficiency in the production of welfare. On an ideological level there had been increasing challenges to traditional views of "care" (based on critiques of dependency, medicalisation and physical segregation)" (Priestley, 1999, p. 39).

In 1986, Sir Roy Griffiths was "commissioned...to develop proposals for the reorganisation of community care" (Priestley, 1999, p. 40) within the difficult financial climate that existed at the time. Two years later, his report was published (Griffiths, 1988). He recommended that there "should be a system of assessment based on local and individual needs and the development of a market for "care" that would provide greater choice and diversity in meeting such needs" (Priestley, 1999, p. 40). Griffiths recommended that social services departments should be responsible for "assessing needs…setting priorities…developing (care) plans…(and) for arranging the necessary service provision to fulfil that plan" (Priestley, 1999, p. 40).

Griffiths' plan was taken forward in the White Paper *Caring for People* (DH et al., 1989) and implemented in the National Health Service and Community Care Act (NHSCCA) 1990. Later policy (DH et al., 1990) and practice guidance (DH et al.,

1991b) set out how practitioners should put this "care planning" process into practice, detailing how "care managers" would assess needs and be responsible for producing "care plans", arranging services and monitoring services. Whilst the rhetoric within *Caring for People* emphasised that community care was to be built around "services that respond flexibly and sensitively to the needs of individuals and their carers" (DH et al., 1989, cited by Priestley, 1999, p. 42), both the Department of Health (DH et al., 1991a) and the Audit Commission (Audit Commission, 1992) showed that social services departments were still fitting individuals into services rather than designing services to meet their specific needs. Priestley (1999) argues that community care policy and practice is built around the "assumption...that disabled people are dependent and need "care"" (p.43), the "assumption...that this need arises as a result of personal inadequacy" (p. 47) and the "assumption that the needs of disabled people should be addressed (in the public sphere at least) through separate institutions of welfare production" (p. 49).

Much of the literature criticises community care practice for failing to meet disabled people's needs (e.g. Morris, 1993; Zarb and Nadash, 1994; DH, 1998; Priestley, 1999; Glasby and Littlechild, 2002; Swain et al., 2004; DH, 2005; PMSU, 2005; DH, 2006; Oliver and Sapey, 2006). The government's response to this has been to "modernise" services (DH, 1998) and to promote other personalised support systems such as direct payments and individual budgets.

The Independent Living Fund (ILF)

The Social Security Act of 1986 "announced measures to replace Supplementary Benefit with Income Support" (Glasby and Littlechild, 1988, p. 13). Set up as an "independent trust fund" (Glasby and Littlechild, 2002, p. 14) for five years with an initial budget of £5 million, the Independent Living Fund (ILF) "gave disabled people the opportunity to receive cash payments in order to purchase personal assistance" (Glasby and Littlechild, 2002, p. 13). This scheme turned out to be extremely successful and, by the end of the five years, it was supporting around 22,000 people at an annual cost of £82 million.

Kestenbaum, who carried out an ILF study in the early 1990s, found that recipients valued the ILF for the following reasons:

- "choice of care assistant;
- continuity of care;
- the flexibility of care arrangements;
- the greater availability of respite options;
- enhanced self-respect;
- choice" (Kestenbaum, 1993a, pp. 32-41, cited by Glasby and Littlechild, 2002, p. 14).

Indeed Kestenbaum even went as far as saying that this was the "preferred option" for many disabled people as opposed to statutory services (Kestenbaum, 1993b, p. 35, cited by Glasby and Littlechild, 2002, p. 14). Unfortunately, the very success of the ILF meant that there was an increasing financial burden on the government and that its recent community care reforms were now under attack. The success of the ILF also placed pressure on the government to reform its long-standing restrictions on cash payments as a means of service provision from the NAA 1948. After the five years were over, the government replaced the ILF with two funds:

- "The Independent Living (Extension) Fund would continue to administer payments to recipients of the original ILF.
- The Independent Living (1993) Fund would accept new applications but on a different basis. Henceforth, disabled people receiving at least £200 worth of services per week from their local authority may receive a maximum of £375 from the Fund. Crucially, the new Fund was to be restricted to people aged under 66 at the time of their application" (Hudson, 1993; ILF, 2000; cited by Glasby and Littlechild, p. 15).

This effectively meant that all new applications would be used to ""top up" existing care packages", which was "widely interpreted as a retrograde step which emphasised professional control rather than user-led services and independent living" (Glasby and Littlechild, 2002, p. 16).

It is important to note that the ILF, whilst giving service users more choice and control than community care services, was not without its problems – mostly legal and managerial problems (Glasby and Littlechild, 2002, p. 16). On top of this, the ILF "revealed the potential conflicts which can arise between the aims of

the Independent Living Movement and the desire of central government to limit public expenditure" (Glasby and Littlechild, 2002, p. 16).

At the time of writing, the ILF trusts are about to be replaced with one Trust Deed responsible for both funds. Whilst it is felt that the ILF does give service users more choice and control than traditional social work service provision, a recent review of the ILF (Henwood and Hudson, 2007) highlighted the many barriers associated with the ILF, including discriminatory eligibility criteria, its use of medicalised notions of disability, poor transparency about its management and operations, insufficient and inaccessible information about the Funds, and an inflexible system. It will be important to improve this system quickly because the ILF is one of the funding sources being used for individual budgets.

Direct Payments

Whilst their impact has been very limited, it should be noted that direct payments have been available in Scotland since the Social Work (Scotland) Act was passed in 1968. Following sustained campaigning by the Disabled People's Movement, in particular a study about ILF by Zarb and Nadash (1994), the Community Care (Direct Payments) Act (CC(DP)A) was passed in 1996. This permitted local authorities to give direct payments to disabled people who had been assessed under the National Health Service and Community Care Act 1990 as being eligible for community care services (DH, 1996). Before the CC(DP)A 1996 was introduced, debates about direct payments centred around, on the one

hand, the "choice and control" given to disabled people and the "cost-efficiency" of previous schemes, against, on the other hand, the "complexity of administering direct payments and doubts about the capacity of local authorities to manage payments schemes" as well as "concerns that direct payments would reduce local authorities' flexibility in providing services and divert resources from other priority areas" (Zarb and Nadash, 1994, pp. 9-11, cited by Glasby and Littlechild, 2002, p. 25). This was also being introduced at a time when social services departments were in the middle of significant organisational change with the introduction of the NHSCCA in 1990.

When the CC(DP)A came into force in the UK in April 1997, anyone presenting with community care needs under the age of 65 became eligible to receive direct payments (DH, 1996). Entitlement was "then extended to older people...and later to other groups such as 16 and 17 years olds and parents of disabled children" (Riddell et al., 2006, p. 2) by amendments to legislation in all areas of the UK. The Health and Social Care Act 2001 and the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003 (HMSO, 2003) placed a duty on local authorities to offer direct payments to eligible service users. Until then, local authorities had not been required, by law, to offer direct payments. In 2003, a new direct payments target was implemented in the performance indicators, which all social services departments are required by government to meet, which adds to the imperative on local authorities to provide direct payments.

Much direct payments policy and guidance (DH, 2003a; HMSO, 2003), and previous studies on the benefits of direct payments (Kestenbaum, 1993; Zarb and Nadash, 1994) as well as current direct payments research (Stainton and Boyce, 2004) indicate that direct payments have the potential to give disabled people increased control and choice over their lives. However, most studies reveal that implementation of direct payments has been slow (e.g. CSCI, 2004; Leece and Bornat, 2006; Riddell et al., 2006; Ellis, 2007).

Riddell et al.'s study, in particular, offers some interesting insights into the implementation of direct payments in the UK. The purpose of the research was "to support future policy development by explaining variation in implementation of direct payments policies in different localities across the UK, and particularly within the context of devolution in England, Scotland, Wales and Northern Ireland" (Riddell et al., 2006, p. 1). The following factors were listed as aiding direct payments implementation: "Effective support scheme; training and support for front line staff; leadership within the local authority; positive attitude of staff; national legislation, policy and guidance; accessible information for service users and carers; demand from service users and carers" (Riddell et al., 2006, p. 10). The following factors were listed as hindering direct payments implementation: "Users' and Carers' concerns about managing direct payments; staff resistance to direct payments; lack of people to work as personal assistants" (Riddell et al., 2006, p. 10). In their conclusion, Riddell et al. (2006) suggested that three

themes were particularly important: "the politics of devolution; local cultures of welfare; and the influence of the disability movement" (p. 16).

In Control and Individual Budgets

Inspired initially by the White Paper Valuing People (DH, 2001), the idea behind in Control was "to help social services departments fundamentally change their social care systems to increase the citizenship of disabled people" (Poll et al., 2006, p. 7). Since then, the government has placed ideas of choice and control firmly on the social care agenda. In their report on In Control, Poll et al. recognise that the Independent Living Movement and the Inclusion Movement are the major influences behind this system. In 2003, In Control was piloted in six locations and, due to its success, is now being tested in more than 80 locations across the UK. In Control, unlike the care management process, is based on seven steps (Poll et al., 2006, p. 10): "Set personalised budget, plan support, agree the plan, manage personalised budget, organise support, live life, review and learn" (Poll et al., 2006, p. 11). In Control has introduced a system called the Resource Allocation System (RAS) which "enables people to know right at the beginning of the process how much funding is likely to be available for their support" (Poll et al., 2006, p. 18). Whilst not wanting to go into too much detail at this stage, In Control's report (Poll et al., 2006) demonstrates that self-directed support gives disabled people more control over their lives and that these developments are supported not only by service users but also, and in the light of the problems associated with the implementation of direct payments (Riddell et al., 2006; Ellis,

2007) more importantly, by social workers and other professionals working with disabled people.

Inspired by the success of In Control, *Improving the Life Chances of Disabled People* (PMSU, 2005), *Independence, Well-being and Choice* (DH, 2005) and *Our Health, Our Care, Our Say* (DH, 2006) introduced the concept of individual budgets into the social care market:

"The idea behind individual budgets is to enable people needing social care and associated services to design that support and to give them the power to decide the nature of the services they need" (DH, 2007a).

Key features of this new approach are:

- "A transparent allocation of resources, giving individuals a clear cash or notional sum for them to use on their care or support package.
- A streamlined assessment process across agencies, meaning less time spent giving information.
- Bringing together a variety of streams of support and/or funding, from more than one agency.
- Giving individuals the ability to use the budget in a way that best suits their own particular requirements.
- Support from a broker or advocate, family or friends, as the individual desires" (DH, 2007a).

This "new approach" addresses support needs and individual circumstances and "is underpinned by the principle of listening to disabled people and acknowledging their expertise in how to meet their needs" with the aim of increasing "the choice and control that people have over how their additional requirements are met" (Morris, 2005, pp. 2-3). There is an expectation that social workers will have to work much more closely with disabled service users and organisations of disabled people in order "to promote self-directed support" (Morris, 2005, p. 4). A total of "13 local authorities are piloting Individual Budgets in order to develop an evidence base for potential national roll out" (DH, 2007a) each using different groups of service users and different RAS to work out which systems work best.

Initial reports suggested that "pilot sites have faced significant challenges in setting up systems and processes for providing Individual Budgets" but that "progress on aligning income streams has been good" (DH, 2007b). In the latest evaluation regarding the Individual Budget pilot projects (Ibsen, 2007), it was highlighted that "there are a wide variety of approaches to the assessment of needs" (p. 1), from more conventional approaches similar to those to be found in community care assessment to self-assessment. Ibsen (2007) found that the RAS led to "some "winners and losers" compared to the existing system" (p. 1) which meant that local authorities were having to put up transitional funding to cover the change-over period for those service users who lost out because of the new system. They also found that there were problems "integrating and aligning

some funding streams" (Ibsen, 2007, p. 2), which appears to contradict those earlier reports. Interestingly, there was some evidence of difficulty in "keeping the packages cost-neutral" due to "new demand from eligible (but previously selfsufficient) users" (Ibsen, 2007, p. 2). Unlike Poll et al.'s report, Ibsen (2007) found many barriers to implementation:

"Barriers to effective training included the perceived professional threat to care managers; resistance to change; the timing of training in relation to the development of the project; and organisational restructuring" (p. 2).

Start-up costs for the individual budget pilots were substantial totalling £546,000 over a two year period, a total which did not include staff salaries (lbsen, 2007, p. 3).

Problems aside, the government believes that individual budgets "should drive up the quality of services" through the control people have over their budget and the ability that this has to "stimulate the social care market to provide the services people actually want, and help shift resources away from services which do not meet needs and expectations" (DH, 2005, p. 35).

Chapter Three

Assessing the financial barriers to independent living

Recent government policy and legislation (DH, 1998; DH, 2001; PMSU, 2005; DH, 2005; DH, 2006) recognised that services, in particular care management procedures, were failing disabled people and highlighted the importance of preventative strategies, services and cash-for-care schemes in enabling disabled people to live more independently. Whilst the inability of local authorities to deliver these changes due to monetary problems was recognised in earlier documents (DH, 1998), these same concerns were notably absent from more recent policy and legislation. And yet the monetary situation has not changed since *Modernising Social Services* was published. In fact the situation is getting worse (LGA, 2006). Many commentators are critical of the government's failure to invest in social care (e.g. Priestley, 1999; CSCI, 2006; Wanless, 2006; LGA, 2006, Holloway and Lymberry, 2007) and of "ever-rising eligibility criteria for access to services" (CSCI, 2006, p. iv). In this chapter, therefore, we will examine more closely the relationship between money and personalised support.

Efficiency savings

With the government expecting local authorities to make "efficiency savings" in the years to come (Gershon, 2004; DH, 2007c), difficult questions have been raised about the "capacity of a system to both empower benefit recipients and cut back the welfare state" (SCIE, 2007, p. 1). The Social Care Institute for Excellence (SCIE) (2007) also raises questions about "policy coherence" with

"tensions between developments in the NHS towards increasing the autonomy of practitioners, and in social care towards empowering service users" (SCIE, 2007, pp. 1-2). They provide evidence which shows that there is a tendency with personalised support systems to underestimate the cost implications which results in problems later on in their development (SCIE, 2007). Their report highlights the need for further research into the cost effectiveness of personalised support systems, a need which has recently been partially addressed by the newly created Office for Disability Issues in a review into the costs and benefits of independent living (Hurstfield et al., 2007).

In the last chapter, it was identified that one of the reasons for introducing community care legislation in 1990 was that it was believed that individual services would save the government money (Priestley, 1999) as opposed to institutional provision which was very expensive. As we have seen, the government specifically requested that Sir Roy Griffiths address the financial implications of these changes in his review. Within this context, therefore, it is clear to see that little has changed with regards to welfare spending. In recent years, increased attention has been given to the way public money is spent on public services. In 2004, Sir Peter Gershon completed the *Independent Review of Public Sector Efficiency* (Gershon, 2004). In the 2004 Budget, the then Chancellor of the Exchequer, Gordon Brown, following recommendations made by Sir Peter, announced "a target to deliver £20 billion of annual efficiency gains by 2007-08, through a 2.5 per cent a year efficiency target for the whole public

sector" (Gershon, 2004, p. 22). Part of the efficiency savings would come about through the loss of 84,000 military and civil service posts between 2004 and 2008. The major targets were the National Health Service (which included social care), which was required to deliver £6.47 billion of efficiency savings, and local authorities which were asked to deliver £6.45 billion of efficiency savings (Gershon, 2004, p. 30). In order to implement these recommendations, the Care Services Efficiency Delivery (CSED) team was set up in June 2004. Its remit was to "work with local councils, the NHS and service providers to develop and support initiatives to make adult social care more efficient" (DH, 2007c).

Every year, the Local Government Association (LGA) reviews the state of social services finances in the UK. In 2005-06, the response rate to its national survey of local authorities was 80 per cent or above. As such, the findings may be considered to be particularly valid. The LGA described the financial climate for 2006-07 as being "deeply worrying" and that "pressures have left a gaping £1.76 billion black hole in funding for social services" (LGA, 2006, p. 1). The report identified several reasons for these funding pressures including: an ageing population; an increase in the number of people requiring care; medical advances which have increased people's life expectancy; increased demand for services; and "the cost of contracts with the independent and voluntary sector…outstripping inflation" (LGA, 2006, p. 1). There is also evidence that reductions in NHS and Supporting People Programme funding has added to the financial burden placed on local authorities (LGA, 2006, p. 6). The LGA is critical

of the fact that the preventative agenda set out in *Our Health, Our Care, Our Say* (DH, 2006) "has not so far been backed up by sufficient investment" and is calling for "a fair and sustainable system of funding" (LGA, 2006, p. 1). In a similar vein, last year Community Care magazine launched its "Stand up for Social Care" campaign to put pressure on the government to invest more in social care.

The impact of financial barriers on eligibility criteria

In 2002, the Department of Health introduced a national system of "eligibility criteria" because it felt that the previous system, whereby eligibility levels were defined by local authorities, had become too varied. From then onwards, needs were to be defined as "critical, substantial, moderate and low" (DH, 2002) with local authorities giving priority to those with critical needs. The government currently believes that "current eligibility criteria allow for early intervention and support" (DH, 2005, p. 39). In this section, it is contended that the facts undermine this belief.

There is widespread recognition that financial pressures have led to "a tightening of eligibility criteria for access to services" (LGA, 2006, p. 6). The LGA's survey, for example, revealed that, whereas the combined percentage of service users receiving support to meet "substantial" and "critical" needs was 57.4 per cent in 2004-05, this figure had risen to 67.6 per cent in 2005-06. It also revealed that "80 per cent of councils" planned to tighten their eligibility criteria in 2006-07

(LGA, 2006, p. 6). In a society where the demand for social care services is increasing (LGA, 2006; Wanless, 2006), rising eligibility criteria means that less service users, nearly all of whom have complex needs, receive social care services. Those that do not meet the eligibility criteria either have to arrange and pay for their own services or, if they do not have sufficient income, people go without services which, in the long run, has the potential to impact negatively on their health and certainly on their ability to live independently. In its latest report, *The State of Social Care in England 2005-06* (CSCI, 2006), the Commission for Social Care Inspection (CSCI) argues that more research is needed to find out about the support needs and circumstances of people who do not meet the eligibility criteria for statutory social care. Many social workers argue that more attention needs to be paid to those who have lower or moderate needs, in other words the preventative agenda (DH, 2005; DH, 2006), because otherwise their needs may become substantial or critical in the future (DH, 2007d).

It has been suggested that,

"For too long social work has been perceived as a gatekeeper or rationer of services and has been accused, sometimes unfairly, of fostering dependence rather than independence" (DH, 2005, p. 10). The truth of the matter is that, due to financial circumstances, social work departments have had to ration resources and limit expenditure to people with substantial and critical needs. Whilst disabled people (e.g. Priestley, 1999;

Gillman, 2004, p. 254; Oliver and Sapey, 2006, p. 176) and social work

academics and social workers (e.g. Jones, 2002; McDonald, 2006) accept the fact that social work departments are under-resourced, the government believes that extra resources can be found through efficiency savings.

Based on what we already know about the financial problems social services departments face and the fact that the Labour government has already indicated that extra investment will have to come through efficiency savings, it is highly unlikely that the financial problems of social services departments are going to disappear in the near future. In all likelihood, eligibility criteria will continue to be largely based on critical and substantial support needs with fewer service users benefiting from the local authority social care provision. Local authorities must, therefore, find savings in order to invest in the new policy direction in order to give disabled people more choice and control over their lives.

Assessing the cost efficiency of independent living

Two substantial pieces of work have been carried out which aim to evaluate the costs and benefits of personalised support schemes – Zarb and Nadash's research study entitled *Cashing in on independence: Comparing the costs and benefits of cash and services* (Zarb and Nadash, 1994) and the Office for Disability Issues's (ODI) recent study *The cost and benefits of independent living* (Hurstfield et al., 2007). These studies reveal far more than simply the economic benefits of different forms of personalised support, although this is very

important, including as they do information about the ability of these types of schemes to enable disabled people to live more independently.

Zarb and Nadash (1994) interviewed 70 disabled people for the purpose of their study, 35 of whom were receiving indirect or direct payments through their local authority or through the ILF and 35 of whom were receiving services organised by their local authority. They also carried out a national postal survey to local authorities to find out whether they supported direct payments. The study showed that disabled people receiving payments were more likely to receive "higher quality support...(and) a greater degree of choice and control" than people using direct service provision and that payments schemes met "a wider range of assistance needs" (Zarb and Nadash, 1994, p. 5). They were also more likely to "have markedly higher levels of overall satisfaction with their support arrangements than service users" which was largely determined by the "control" they gained and the "reliability" of support arrangements (Zarb and Nadash, 1994, p. 6). Interestingly those people receiving payments indirectly or directly from their local authorities felt that this provision was more suited to their needs than the support ILF recipients received. This was attributed to the fact that they had greater "access to support and advice about organising their support" (Zarb and Nadash, 1994, p. 6).

In terms of the financial costs of different forms of personalised support, the study found that "support arrangements financed by direct/indirect payments are,

on average, between 30 and 40 per cent cheaper than equivalent service based support" (Zarb and Nadash, 1994, p. 7). This was due largely to the difference between the costs of administering the different support arrangements. Although there was a ban on local authorities making direct payments to service users, Zarb and Nadash (1994) found that "just under 60 per cent of authorities...were already operating payments schemes" (p. 7), most of whom were making indirect payments to service users. Ninety per cent of these "indicated that they would make payments if legislation permitted" (Zarb and Nadash, 1994, p. 8). This study greatly strengthened the case for introducing such legislation and, as we have seen, the 1996 CC(DP)A was introduced in 1996.

In their study, Hurstfield et al. (2007) carried out an extensive review of the literature "on the potential costs and benefits associated with investment in IL (Independent Living) support, as compared to more conventional forms of service provision" (p.7). They also used five case studies to illustrate the costs and benefits of different independent living scenarios, which involved "in-depth face-to-face interviews with service recipients, strategic policy stakeholders and service delivery representatives" (Hurstfield et al., 2007, p. 8). For the purpose of their study, "conventional forms of service provision" refers to community care services and independent living support refers to the ILF, direct payments, individual budgets and In Control. The study refers to costs and benefits at a service delivery level and at a macro level.

Whilst it has been argued that there are significant problems with social services budgets (LGA, 2006), which is made worse by efficiency targets and underinvestment, the Government have a point when they argue that cost savings should and indeed can be made. Local authorities have not struggled to make efficiency savings since 2004, although this has resulted in eligibility criteria rising over that time.

"By the end of September 2006 departments and local authorities reported annual efficiency gains totalling £13.3 billion...(and a) gross reduction of nearly 55,000 civil service posts, and over 10,500 posts had been relocated" (HM Treasury, 2006, p. 24).

Indeed, Hurstfield et al. (2007) found a "variety of inefficiencies involved in the delivery of conventional types of support" (p. 88). Some of the research participants even "suggested that 20-30% of social services expenditure is wastage" (Hurstfield et al., 2007, p. 88). At the service delivery level, for example, they pointed out that "local authorities are encouraged to enter block contracts for services which offer initial cost savings, but limit flexibility and incur greater costs in the long term" or that many local authorities commission services with private organisations who take on contracts to make "significant profits" (Hurstfield et al., 2007, p. 88). Wastage also occurs, they point out, when social workers do not assess needs effectively and people end up receiving services "which are not necessarily what individuals want or need" or when individuals are assessed for either NHS or local authority aids and adaptations and they end up not using

these provisions because they "are not properly suited to their needs" (Hurstfield et al., 2007, p. 89).

In terms of benefits at the level of service delivery, it was argued that conventional forms of service delivery can drive down staffing bills and product costs. It was also argued that they "may still be able to provide choice and control for disabled people" (Hurstfield et al., 2007, p. 89) and that many service users do not necessarily want or are not capable of using other independent living solutions. On a macro level, research participants were unable to come up with any benefits for using conventional types of support. There were, however, many costs. In large part, this is due to the fact that service users using conventional support are often unemployed or that staff do not believe they are capable of working. Disabled people, for example, are "twice as likely to have no educational qualifications, (and) more likely to be unemployed or economically inactive" (Labour Force Survey 2005, cited in DRC, 2006, cited by Hurstfield et al., 2007, p, 11) than non-disabled people. This "clearly has an impact on tax revenues, National Insurance and Pension Contributions" (Hurstfield et al., 2007, p. 89) and means that more people are claiming welfare benefits. If more disabled people were enabled to get back into work, this would reduce the annual benefits bill substantially and increase the amounts collected in taxation leaving more money to spend on public services. There is also evidence that conventional forms of support lead to "dependency" which may result in physical

and mental health problems which "adds to NHS costs of addressing these symptoms" (Hurstfield et al., 2007, p. 91).

As far as the costs and benefits of independent living schemes are concerned, Hurstfield et al. (2007) suggest that the "transformational costs are likely to be considerable", not only in terms of "training and administration costs" and in terms of developing local authorities commissioning strategies to be "more responsive and demand led" but also because "resources are substantially tied up in "bricks and mortar" in the forms of institutional and residential care settings". However, they are confident that these short-term costs will "be offset in the medium and long term" (p. 92). There will also be "continuous costs" which refer to the "practical, financial and emotional support services" (Hurstfield et al., 2007, p. 92) which enable service users to manage the ILF, direct payments and individual budgets as well as information provision and education about cash-forcare schemes. It is noted that independent living support is "labour intensive" (Hurstfield et al., 2007, p. 92), which will add to the total costs of implementing this type of support. Their report makes clear that local authorities are likely to bear the brunt of these costs at the level of service delivery and that savings will come through increased tax revenue and reduced welfare benefit expenditure at a macro level. They argue that the Government will need to find ways to "investigate how to transfer some of the benefits back to service providers in order to incentivise them to embrace wholesale IL implementation" (Hurstfield et al., 2007, p. 103) as there are significant costs which will arise in making the

transition and also attitudinal barriers to overcome. In terms of the benefits of independent living support, there is evidence that they deliver "better value for money" and that service users "will be able to make more efficient and effective use of resources" (Hurstfield et al., 2007, p. 93). It is also felt that they have the potential to drive up the "quality of provision and, therefore, outcomes for both individuals and employees" (Hurstfield et al., 2007, p. 93).

Whilst these findings do add weight to the view that independent living options are more cost effective than conventional forms of social work support in the medium and long-term, it is likely that this transition will take many years to complete. To illustrate this point, the CSCI pointed out that "direct payments only accounted for around £1 in every £100 of social care expenditure in 2004-2005" (CSCI, 2006, p. xi). The numbers of people receiving direct payments has risen fairly substantially since 2003 (LGA, 2006; NHS, 2007) but this only accounts for a tiny proportion of the total number of people receiving community care services. In light of the evidence portrayed in both chapter two in relation to the Individual Budget Evaluation (Ibsen, 2007) and Hurstfield et al.'s (2007) evidence, the transitional short-term costs of transferring to independent living are likely to be considerable. Beresford (2007) and Barnes and Mercer (2006) are both critical of the government's use of the cost efficiency argument when talking about independent living because it devalues disabled people's lives. Many disabled people argue that disabled people should have a right to live

independently (Zarb, 2003; Morris, 2005), which is currently denied them under the existing legislation.

The "Disability Category", capitalism and financial barriers

Many studies (e.g. Ellis, 2007; Hurstfield et al., 2007), as well as disability studies literature (e.g. Barnes, 1991a; Barnes and Mercer, 2006; Oliver and Sapey, 2006; Priestley, 1999; Swain et al., 2004), highlight considerable social and attitudinal barriers to the concept of independent living and personalised support schemes. In her classic work The Disabled State, Stone argues that "all societies have at least two distributive systems, one based on work and one on need" (Stone, 1985, p. 15). The tension between these two systems, she argued, poses problems for the State, which has to find ways of supporting those people who are unable to work and who are in need. Since the 20th Century, welfare benefits have been provided to those who are unable to work or to those who are in need. The money to fund these benefits comes from taxing those who are able to work. Over the last sixty years, therefore, different governments have argued over who should be able to claim benefits and the rate at which benefits should be set. Stone's (1985) analysis of disability as a "formal administrative category" (p. 27) is particularly relevant for social work today where disabled people's needs are generally defined by social workers and where eligibility criteria have been set to determine who receives local authority social care support.

Oliver (Date unknown) similarly argues that disability is a "category" (p. 3):

"The production of disability is nothing more or less than a set of activities specifically geared towards producing a good – the category disability – supported be a range of political actions which create the conditions to allow these productive activities to take place and underpinned by a discourse which gives legitimacy to the whole enterprise" (Oliver, date unknown, p. 3).

Oliver believes that the capitalist economy, with its ideas about the centrality of work within society, is largely responsible for creating the disability category, and that capitalism itself has led to disabled people's "economic and social exclusion" (Oliver, date unknown, p. 6). Disability, he argues, has for a long time been viewed as "an individual problem requiring medical treatment" (Oliver, date unknown, p. 7). The discourse underpinning the disability category is therefore one which sees disability as a problem which can be improved or cured by medical intervention. Like many other disability activists, Oliver advocates instead the social model of disability and services which are controlled and run by disabled people. It is important to note that the focus of the social model of disability is on social and environmental barriers rather than on impairmentrelated issues. Disabled people do not deny that their impairments influence the way in which they live or "the importance or value of appropriate individually based interventions" (Barnes, 2005, p. 7). Instead, the social model of disability "draws attentions to their limitations in terms of furthering their empowerment and inclusion in a society constructed by non-disabled people for non-disabled people" (Barnes, 2005, p. 7).

When discussing the White Paper Caring for People (DH, 1989), Barnes (1991b) predicted that "these proposals are unlikely to lead to an increase in choice, control, accountability and autonomy for the overwhelming majority of disabled people" (p. 2). His reasons for this prediction centred on the resources disabled people have at their disposal, which he argued to be inadequate, and on the way professionals would still have control over identifying need and defining eligibility for services. Like Zarb and Nadash (1994) and Hurstfield et al. (2007), Barnes was critical of the way large proportions of money was being spent on institutional care provision for disabled people and on health and social services aimed at curing people of their impairments or helping them to live with their impairments. Importantly, he identifies further with Oliver's (date unknown) argument about disability being a "good" when he argued that "the lion's share of any money allocated to services for disabled people will go to service providers" (Barnes, 1991b, p. 3), large proportions of which, he said, was spent on staff wages. With so much money being spent on institutional care and staff wages, there is less money available to enable disable people to live independently. The point about social workers still being in control of the assessment process is crucial. Whether it is through direct service provision or by giving disabled people direct payments to organise their own support arrangements, service users are still required to meet the needs they are assessed as being eligible for and eligibility is defined by social work professionals. Of these two options, however, it is clear that many disabled people find direct payments give them more choice

and control (Priestley, 1999; Glasby and Littlchild, 2002; Leece and Bornat, 2006).

Zarb (2003) argues that, due to rising eligibility criteria, "...in a lot of cases, the minimum support people can expect to receive does not guarantee much more than simply being able to stay alive" (pp. 2-3). He argues that disabled people face discriminatory attitudes and policies when seeking support to live independently:

"Put crudely, removing all of the barriers to disabled people's full social and economic participation is considered to be simply too expensive when compared to meeting the costs of other social and economic priorities. In practice, this means that needs are defined by what public support systems are able, or prepared, to afford rather than by the actual barriers that disabled people face in their day to day lives" (Zarb, 2003, p. 3).

For Zarb (2003), this failure to invest in independent living is discriminatory because it devalues the status of disabled people in society and disregards their human as well as civil rights.

Chapter Four

The social work role in relation to funding

In the last chapter, it was argued that financial barriers have reduced the ability of personalised support schemes to meet disabled people's independent living requirements. This is, in large part, due to increasing eligibility criteria which restrict the numbers of service users receiving services and are based on risk to people's independence. Bearing in mind the difficulties which these financial constraints pose for social work departments, it is important also to understand the role which social workers, social work managers and service commissioners play in relation to funding. It will be argued that this has had a negative impact on disabled people's relationships with social workers, something which service users value very strongly (Beresford, 2007).

What is social work?

The nature of social work and the roles of social workers are determined by many different things: legislation and accompanying policy and practice guidance; social policy; social work values; theory and models of practice; codes of practice; and social work standards. In two recent reports on the roles and tasks of service users (Beresford, 2007; Blewett et al., 2007), it was argued that social workers have complex roles and tasks to perform. There are many different definitions of social work. For example, *Options for Excellence* (DH & DfES, 2006) says:

"Social work is a problem-solving activity, carried out by the worker through relationships with the individual, family and community. Social work is usually needed when individuals, families or communities are facing a major and often life changing problem or challenge. Social workers help individuals and families to achieve the outcome they want in the ways they prefer" (p.49, cited by Blewett et al., 2007, p. 5).

In this definition, the importance of social work intervention in times of crisis is stressed. The importance of preventative services in the lives of individuals, families and communities, which is considered to be vitally important in the new social policy setting, is left out. Blewett et al. (2007) highlight a number of key principles and components of social work. The following "core principles" are felt to underpin social work:

- "It is a problem-solving activity
- The focus is on the whole of a person's/family's life, their social support network, their neighbourhood and community
- The value system is based on human and civil rights
- The social model is the framework for practice
- Social workers work <u>with</u> individuals, families, groups and communities to define together the outcomes they are seeking
- The process and the relationship are a core part of the service and can represent a service in itself

 The purpose of social work is to increase the life chances and opportunities of people using services by building on their strengths, expertise and experience to maximise their capacities" (Brand et al., 2005, pp. 2-3, cited by Blewett et al., 2007, p. 5).

Whilst it is positive that the "social model" framework is encouraged in these principles, the fact that social work is increasingly taking place in multidisciplinary settings means that the individual model often takes priority to the neglect of social and environmental factors. The importance of the social work "process" and the "relationships" which social workers have with service users is something which Beresford (2007) notes as being crucially important for service users.

The following are felt to be the core components of social work:

- "a) Understanding the dynamic between the individual and the social
- b) Social work and social justice
- c) the transformatory significance of the relationship
- d) the enabling role of social work
- e) the therapeutic role of social work
- f) the management of risk to both the community and the individual
- g) the evidence base for social work practice" (Blewett et al., 2007,
 - p. 6).

Whilst these are all important components of social work, the extent to which social workers are able to work, for example, towards issues of social justice, is questionable when there is currently an emphasis on the importance of risk management and on protecting "vulnerable" adults (DH, 2000; DH, 2005). There is also considerable evidence (Jones, 2002; Blewett et al., 2007, pp. 8-9; Beresford, 2007) that bureaucratic statutory regimes have impacted negatively on social worker-service user relationships.

In terms of social work values, one of the major changes in the 1990s was the need to listen to the views of service users which led to the development, by social workers and social work academics, of anti-oppressive practice (Thompson, 2001). The purpose of anti-oppressive practice is to "understand how inequalities and discrimination feature in the social circumstances of clients, and in the interactions between clients and the welfare state" (Thompson, 2001, p. 21). Whilst this was an important development at the time, the fact remains that disabled people still believe that there are serious attitudinal and environmental barriers which statutory social work needs to overcome (Swain et al., 2004; Barnes and Mercer, 2006; Oliver and Sapey, 2006).

The changing policy context

When New Labour came to power in 1997, it was felt that public services were in need of "modernization" (Holloway and Lymberry, 2007, p. 379). The 1998 White Paper *Modernising Social Services* (DH, 1998) promoted this principle for health

and social services. It was believed that "pooled budgets" between health and social care would encourage greater "collaboration" between these agencies. The government placed an emphasis on health and social care integration with professionals having a "skills mix" and there was support for joint working in multi-disciplinary settings. Other key ideas in terms of the modernisation agenda were "standardization across user/patient groups", "performance measurement" with much greater use of targets, a "focus on outcomes, ensuring that *social care services represent the best possible value for taxpayers' money*" and the use of evidence-based policy and practice (Emphasis added by author, Holloway and Lymberry, 2007, p. 379). In terms of community care services, Fair Access to Care Services (FACS) (DH, 2002) introduced the notion of "eligibility criteria" which were largely based on notions of risk to people's independence.

As far as joint working between health and social care agencies is concerned, differences have existed between health and social care since the National Health Service (NHS) was set up in 1948. NHS services are "generally free at the point of need, whereas a service provided by the social services department is generally subject to a means-tested charge" (Clements, 2004, p. 258). The difficulties arise because there are differing opinions about what health care and social care needs are and, consequently, there are arguments about who will pay for these services. Whilst there is a need for health and social care agencies to work together, these problems appear to have been accentuated by Government policies aimed at encouraging closer co-operation (DH, 1998; DH, 2006) and by

legislation, such as the Health Flexibilities Act 1999, which extends the duties, established by section 22 of the NHS Act 1977, on local authorities and the NHS to "co-operate with one another" (Clements, 2004, p. 260). In practice, however, "the reality is all too often a jumble of services fractionalised by professional culture and organisational boundaries and by the tiers of governance" (Clements, 2004, p. 259).

Another key development in social care has been the growing need to address adult protection issues (Holloway and Lymberry, 2007, p. 381). This was heralded by the publication of *No Secrets* (DH, 2000), which "represented a key stage in the acceptance that the abuse of vulnerable adults is a major social problem requiring a co-ordinated approach by statutory agencies" (Holloway and Lymberry, 2007, p. 381). Social workers have taken on responsibility for investigating adult abuse and "providing support to those people who have been the victims of it" (Holloway and Lymberry, 2007, p. 381).

Care management, direct payments and the social work role in relation to funding

The NHSCCA 1990 "marked a major development in the organisation and funding of social services for adults" (Blewett et al., 2007, p. 14). Social services departments took over responsibility for funding residential and nursing home care and, therefore, the responsibility for assessing service users' accommodation needs. This Act also meant that the "roles of purchaser and

provider were split with local authorities having to develop the role of service commissioner, looking to the voluntary and private sector to provide the actual service" (Blewett et al., 2007, p. 14). At the same time, the new role of care manager was created to take on care management responsibilities on behalf of service users. There has been considerable progress since 1990 in terms of legislation and guidance about working with different service user groups. So, for example, social workers working with people with learning disabilities follow the guidelines set out in *Valuing People* (DH, 2001) about the importance of "person-centred planning", whereas mental health social workers are required to follow the Mental Health Act 1983 and to use the "care programme approach" in their work with people with mental health problems.

So far as funding is concerned, however, the most crucial development recently has been *Fair Access to Care Services* (FACS) (DH, 2002), which gave instructions as to how local authorities should organise "presenting" and "eligible" needs with a set system of four different categories of eligibility criteria: critical, substantial, moderate and low. As was made clear in chapter three, most local authorities have increased their eligibility criteria to substantial or critical, which are for those service users with complex needs. Social workers play a vital role in terms of assessing disabled people's needs and, consequently, determining their access to either direct services or direct payments.

Assessment is a key social work role. Under Section 47 of the NHSCCA 1990, local authorities have a duty to assess the needs of disabled people if they believe that they could benefit from community care services. As the assessors of need, social workers are responsible for finding out about disabled people's needs and for determining which of those needs are eligible for services. Unfortunately, service users are critical of the way social workers assess their needs (e.g. Gillman, 2004, p. 254; Beresford, 2007, p. 45) and, as was identified in the chapter above, this can lead to resources being spent which do not need to be spent. Beresford (2007) lists the main problems which service users have with social work assessments:

- "It being based on "professional" rather than service user definitions of issues and problems;
- That these are still not necessarily informed by "social" or "barriers" based models;
- Instead they continue to be based on deficit models of service users, only offering support where "inability" is identified, rather than seeing support as a means of enabling ability and supporting preventative approaches;
- While they are meant to be "professionally-led", they are still significantly budget-driven" (Beresford, 2007, p. 45).

Another problem is that, following assessment, many disabled people find that they are not eligible for social work support and so the service planning and

delivery process does not even begin, which is, again, a waste of social work resources (Beresford, 2007, p. 18).

Instead, disabled people have pushed the self-assessment agenda forward (Priestley, 2004; Oliver and Sapey, 2006). Self-assessment is self-explanatory referring to the way disabled people assess their own needs for support (with support if necessary), the point being that disabled people understand their needs better than social workers. The concept of self-assessment was supported by the Central Council for Education and Training in Social Work (CCETSW) as early as 1991 and more recently by the Social Care Institute for Excellence (SCIE) (Oliver and Sapey, 2006, p. 82). Despite this, self-assessment has not been widely used by local authorities and, following pressure by the disabled people's movement, the government has recently begun to push the idea in policy documents and legislation (DH, 2005; PMSU, 2005; DH, 2006).

Some social workers are still sceptical of such a move:

"Self-assessment, that's a joke. If we let them assess their own needs, they'll just want everything. We can't just pay for what they say they need. We're the ones who have to assess what they need otherwise they'll think they can have the world" (Ellis, 2007, p. 7).

This is rather extreme example but does show the power which this one social worker believes they have a right to exert over service users and the financial

constraints under which they are working. In a similar vein, Oliver and Sapey (2006) argue,

"the continued emphasis on budgets limits the extent to which local authorities are prepared to relinquish their control in the determination of individual need – self-assessment requires a partnership between social workers and disabled people which threatens that control" (pp. 178-179).

Whilst there is clear evidence that attitudinal barriers amongst social work professionals, policy officers and local politicians limit the implementation of personalised support schemes (CSCI, 2004; Riddell et al., 2006; Ellis, 2007), there is also evidence that many positively support such schemes because of the positive difference that they make to the lives of disabled people and because of the more positive relationships which social workers assume in enabling and empowering service users in their use of direct payments and individual budgets (SCIE, 2005). It is also important to remember that, even if self-assessment is used, social work departments have limited resources and are still only able to fund those people whose needs are eligible under FACS (DH, 2002).

The government's modernisation agenda has meant that social workers now need to pass through different layers of bureaucracy before they are able to organise services for disabled people (Jones, 2002). Social workers have to put together a care plan which covers each hour of support required by the disabled person before presenting their case to a resource panel, usually made up of

social work managers, who decide whether the disabled person is eligible for support and how much funding will be allocated for the support. Glasby and Littlechild (2002) suggest that increasing eligibility criteria has the effect of "squeezing direct payment packages and allowing less and less time for specified activities" (p. 111). This additional layer of bureaucracy was not envisaged by Griffiths in his report to the government in 1988. Instead, "…care management was to be linked with the devolution of financial responsibility to care managers but it seems that this has not happened often in practice" (Blewett et al., 2007, p. 15).

There is a great deal of difference between packages of support which are organised by care managers and direct payments, whereby disabled people, "trusts" or other "nominees" (DH, 2003a) are given the money to pay for the support needed to meet their care plan. The direct payments system as envisaged by the latest policy guidance (DH, 2003a) is designed to be flexible in order to meet the requirements of the many different types of service users receiving direct payments. Since the money service users are given in their direct payments is public money, local authorities need to account for this money. The policy guidance states:

"Monitoring arrangements should be consistent both with the requirement for the council to be satisfied that the person's needs for the service can and will be met and with the aim of promoting and increasing choice and independence" (DH, 2003a, p. 38).

In line with this guidance, local authorities should "aim to ensure that the information that the direct payment recipient is asked to provide is as straightforward and the least onerous possible" (DH, 2003a, p. 38) and, specifically relating to financial monitoring, that "audit arrangements are as simple and straightforward to understand as possible" (DH, 2003a, p. 39).

Apart from the financial difficulties noted in chapter three, Glasby and Littlechild (2002) note a number of other financial problems related to local authorities handling of direct payments. They note in particular problems associated with "inadequate payments" (Glasby and Littlechild, 2002, p. 111) whereby local authorities underestimate direct payments costs resulting in service users having to pay for extra support out of their own income. There are considerable variations in Scotland, for example, between the "hourly rates for PAs (Personal Assistants)...ranging from £3.60 to £11.64" (Glasby and Littlechild, 2002, p. 111). A further problem, related to the monitoring process above, is that the process "can become overly bureaucratic, acting as a disincentive to take up direct payments" (Glasby and Littlechild, 2002, p. 112). Finally, some local authorities have a "tendency...to impose cost ceilings on direct payment packages", a practice which "has been criticised by the government (DH, 1998), which feels that financial ceilings may result in premature admissions to residential care" (Glasby and Littlechild, 2002, p. 113). The National Occupational Standards for Social Work (Topss, 2004) emphasise that social workers need to be upfront with

service users about the financial resources which are available to pay for support and about the ways this money could be provided.

In all likelihood, local authorities have probably adopted these practices as a result of the funding problems highlighted in chapter three. Having said that, these practices clearly disadvantage service users and local authorities should do all they can to adjust their practice in line with government policy and practice guidance and, if this is not possible, to encourage service users to complain using local authority complaints procedures.

Benefits

Since social work departments are entitled to charge for the residential or nonresidential services they provide, under the NAA 1948 and the NHSCCA 1990, local authority officers undertake financial assessments of the service user to see how much they need to contribute to the care package. Recent guidance (DH, 2003b) has been introduced to ensure that local authority charging policies are fair. Some disabled people believe that this charging policy is unfair because it does not take into account the extra costs of living with an impairment (Thompson et al., 1990) and because many disabled people are already on the margins of or living in poverty (Barnes, 1991). The Fairer Charging guidance (DH, 2003b) tries to limit the impact of local authority charging policies on disabled people's benefits and any other income.

As was argued earlier, following the changes to funding structures brought in by the NAA 1948, social workers avoided helping service users to make use of welfare benefits, leaving this task instead to "specialist money advice services" (Glasby and Littlechild, 2002, p. 7), such as Citizens' Advice Bureaux. In some instances, service users have endured financial hardship because social workers have not provided information about the benefits they are entitled to (Barnes, 1991c). McDonald (2006) states:

"Being aware of the range and types of benefits available is a necessary part of effective working in community care. Maximising incomes enables people to buy in resources not otherwise available to exercise choice" (p. 127).

More recently, the National Occupational Standards for Social Work (Topss, 2004) has said that social workers must "have knowledge of…benefits" (p. 4) in order to keep service users informed about what they might be able to receive. Social workers must, therefore, be prepared to advise service users about benefits. Barnes (1991c) warns, however, that

"...the modern welfare benefits system is a major factor in the disabling process because it fails to provide disabled people with an adequate income, compounds their dependence on professionals and professional organisations and, most importantly, does not facilitate their integration into mainstream employment" (p. 1).

Since Barnes wrote this, New Labour has introduced many initiatives to encourage disabled people back into employment, including the New Deal for

Disabled People and Welfare to Work, and has proposed a number of new roles for employment officers in *Improving the Life Chances of Disabled People* (PMSU, 2005). Despite this, "service users frequently experience these pressures to take paid employment as a problematic, crudely conceived and implemented policy" (Beresford, 2007, p. 38) since there are many wider barriers to their employment such as the "lack of flexibility of the labour market and its insensitivity to their needs" or the "poverty traps" or the "high costs and shortcomings of child care provision" (Beresford, 2007, pp. 39-39).

In Control and Individual Budgets – new funding systems and roles

As was made clear at the end of chapter two, unlike the funding systems used in care management and direct payments, both the In Control pilot projects and Individualised Budget pilot project are using the Resource Allocation System (RAS) to decide how much money to allocate to service users. Currently, many different RAS are being developed and tested to see which works best. The Department of Health have "since requested that a single RAS is developed over time covering all groups" (Ibsen, 2007, p. 1).

As far as the social work role is concerned, In Control's mid-way report (Poll et al., 2006) envisaged that care managers would "retain a duty of care" to service users and would "represent the local authority in the contract with the disabled person" (p. 11). They would also "need to agree the support plan and take part in the review" (Poll et al, 2006, p. 11). There was also recognition, however, that

once the disabled person had been allocated their budget, and could "write their own support plans and organise their own support", then social workers could be freed up to "focus on other tasks", such as "working with people who are in complex situations and on the high-cost, out-of-authority placements" (Poll et al., 2006, p. 11). It was recognised that there are many ways in which the money can be managed and that many local authorities are already using these systems. The following people or bodies may be responsible for managing individual budgets: disabled people themselves, representatives, trusts, brokers, service providers and care managers (Poll et al., 2006, p. 33).

Whilst the RAS was not initially created as a cost saving system, Poll et al. (2006) highlight the cost savings which have been achieved so far. On one occasion they compared the costs in five local authorities before and after using the RAS. They found that there was an average cost saving of between twelve and forty-five per cent which is considerable (Poll et al., 2006, p. 68). As a result, they recommend that "authorities use the RAS to identify areas of spending which represent poor value for money" (Poll et al., 2006, p. 68).

Service commissioning

Local authorities, as the "local monopoly purchasers of care services" (DH, 2007d), have been responsible for commissioning services since the 1990 NHSCCA was passed and providing far less services in-house. Since the Labour government was elected in 1997, services have been "modernised" which has

entailed joint working between the NHS and local authorities, pooled budgets, and new service models, such as direct payments and individual budgets, being introduced into the social care market. There are concerns that the NHS and local authorities are not working well together and that services do not meet the needs and expectations of service users (DH, 1998; DH, 2005; DH, 2006; DH, 2007d). As a result, the government has encouraged the NHS and local authorities to work together in partnership, through various laws, such as the Health Flexibilities Act 1999 and *Our Health, Our Care, Our Say* (DH, 2006) and to encourage greater personalisation of services through direct payments and individual budgets. The government wishes to see much closer planning between health and social services in respect to commissioning services which meet service users' needs. It recently published the *Commissioning framework for health and well-being* (DH, 2007e). This was designed to "enable commissioners to achieve:

- a shift towards services that are personal, sensitive to individual need and that maintain independence and dignity.
- a strategic reorientation towards promoting health and well-being;
 investing now to reduce future ill health costs.
- a stronger focus on commissioning the services and interventions that will better achieve health, across health and local government, with everyone working together to promote inclusion and tackle health inequalities" (DH, 2007e, p. 10).

Whilst the government is concerned with both the health and social care aspects of service provision, the Commission for Social Care Inspection (CSCI), is interested purely in the social care aspects. They define commissioning as:

"The process of translating aspirations into timely and quality services for users which – meet their needs; promote their independence; provide choice; are cost effective; and support the whole community" (CSCI, 2006, p. 59).

The CSCI recognises the importance of direct payments and individual budgets for the future of social care, as numbers of recipients are increasing gradually year on year, and believes that this "presents new challenges to strategic commissioners to develop a market responsive and able to offer the range of services people want" (CSCI, 2006, p. 70). The CSCI accepts that local authorities have been under "considerable strain" (CSCI, 2006, p. 77) due to financial pressures but that, despite this, it has still been able to make efficiency savings. The CSCI believes that local authorities needs to have a "strategic vision for achieving efficiency gains...in the domain of commissioning" and that, so far, many local authorities have not had such a strategy which "means that opportunities for further efficiencies may be lost" (CSCI, 2006, p. 78). For example, "resource allocations continue to follow traditional patterns and there is an inadequate appreciation of costs and therefore control of costs" (CSCI, 2006, p. 82). Bearing in mind the cost savings that are achievable through the use of direct payments and individual budgets, it is possible that more money could indeed be saved as a result of such a strategy. There, therefore, needs to be

"long-term financial planning and resource allocations reflecting need and good control of costs" (CSCI, 2006, p. 82).

Disabled people have picked up this theme in relation to Centres for Independent Living (CILs) and other organisations which are controlled and run by disabled people. These support organisations are crucial in terms of giving disabled people help to manage direct payments and in terms of peer support, information, advice and guidance. The government also supports their development:

"By 2010 each locality...should have a user led organisation modelled on existing Centres for Independent Living" (PMSU, 2005, p. 76).

Unfortunately, research by Priestley (1999), Riddell et al. (2006) and Barnes and Mercer (2006) shows that organisations of disabled people are really struggling financially and that, often, this is because they have not been able to compete with the voluntary and independent sector who have been undercutting their prices and winning service contracts with local authorities. Their research shows that "the limited and mostly short-term nature of financial support available to user-controlled services has acted as a sever constraint on the level and range of service provision" (Barnes and Mercer, 2006, p. 160) available to disabled people. Service commissioners should take account of this situation when deciding how best to go forward with direct payments and individual budgets in the future as, in the eyes of service users (Barnes and Mercer, 2006; Beresford,

2007), these organisations provide better value for money than services provided by voluntary or independent sector organisations. In addition, Barnes and Mercer (2006) point out that "both the PMSU document (PMSU, 2005) and the Green Paper (DH, 2005) contend that improving the life chances of disabled people and ensuring their independence, well-being and choice can be achieved *without additional funding*" (Emphasis added by author, Barnes and Mercer, 2006, p. 178). They believe that this seriously undermines the ability of local authorities being able to promote independent living options "given that there is a wealth of evidence that local authority support for…independent living-type services…has been patchy and unenthusiastic" and that this continues to be the case today (Barnes and Mercer, 2006, p. 179). They argue, instead, that the government needs to consider seriously the need to invest further in social care and, particularly, investment in organisations which are run and controlled by disabled people.

Chapter Five

Conclusion

The aim of this dissertation was to examine whether financial barriers have an impact on the ability of personalised support systems to provide choice and control to disabled people and, in relation to the social work role, how financial difficulties impact on social workers' relationships with disabled people.

In chapter two, it was argued that the link between social work and money goes back as far as the Poor Law Act in 1601 and the setting up of the COS which sought to provide financial support to disabled people. This link, it was argued, was broken when the 1948 NAA determined that the State would be responsible for benefits and social work for welfare issues. Throughout the nineteenth and twentieth Century, there was a rapid expansion of institutions which dealt with the needs of disabled people. It was argued that public expenditure at the time was rising sharply and the government were seeking ways to limit expenditure, especially welfare expenditure (Priestley, 1999). This led, eventually, to the community care reforms of the late 1980s/early 1990s.

From the 1970s, disability activism from within the Independent Living Movement and Disabled People's Movement encouraged disabled people to re-define independent living with an emphasis on the choice and control which they have over their lives. The ILF was a means by which disabled people could obtain financial support to pay for their support arrangements and proved to be so

successful that the government needed to reform the process in a desire to limit its public welfare expenditure. A few years later, direct payments were made legal through the CC(DP)A 1996. Direct payments got off to a slow start but the numbers of disabled people using direct payments increased substantially when the government placed a duty on local authorities to provide direct payments (DH, 2003). Finally, In Control and individual budget pilots were established in the twenty-first Century. Using a different system of assessment and funding, this form of personalised support has been shown to improve disabled people's ability to live independent lives whilst also being shown to be more cost-effective than community care service provision.

In chapter three, it was argued that the government has been trying to limit public expenditure and make efficiency savings for a considerable amount of time now. Whilst overall community care expenditure has actually increased (NHS, 2007), this has not had the desired impact of increasing service activity or improving services. Instead, the government's desire to make efficiency savings (Gershon, 2004), and the resulting underinvestment in social care (Barnes and Mercer, 2006; LGA, 2006), has meant that eligibility criteria have risen steadily so that the majority of people now eligible for community care have substantial or critical needs. Those people who have moderate or low level needs are, consequently, missing out on local authority support, something which has been criticised by social workers (DH, 2007d) and the CSCI (CSCI, 2006) itself. If the government

fails to address the need for further investment in social care, it will fail to provide more preventative services to service users.

As far as the cost efficiency of personalised support goes, it is important to remember that there is still very little hard data available on which to base the following conclusions. The two research reports (Zarb and Nadash, 1994; Hurstfield et al., 2007) used in this dissertation indicate that personalised support systems are cost effective, particularly on a medium and long-term basis. The evidence does, however, indicate that personalised support systems are costly to set up and so short-term costs are likely to be considerable. Both of these research reports highlighted, as opposed to "conventional support" arrangements where their was less choice, control and flexibility, that independent living options gave disabled people more choice and control over their lives. Whilst the current research highlights the short-term costs of independent living options fairly well, more research is required in order provide evidence to the government, policy makers and planners, and service commissioners, that independent living options can be cost effective on a medium to long-term basis. It is also important to recognise that disabled people feel that that the cost effectiveness argument, whilst they acknowledge that there is a need to contain costs, should not come before disabled people's human and civil rights and, so far as independent living is concerned, that disabled people should have a right to independent living (Zarb, 2003; Morris, 2005).

In chapter four, it was argued that social work is a complex job and that the relationship between the social worker and service user is a vital component of that job. It was argued that this relationship is made more difficult by the gatekeeping role which social workers and their managers have in relation to needs assessment. With regards to direct payments and other independent living options, the attitudes of social workers are critical to their implementation. This dissertation found evidence that there is still much scepticism about direct payments (e.g. CSCI, 2004; Leece and Bornat, 2006; Riddell et al., 2006; Ellis, 2007) although there is also considerable support for them too (SCIE, 2005). In relation to current government policy (PMSU, 2005; DH, 2005; SH, 2006), which stresses the importance of direct payments and individual budgets, there is a vital need to train social workers and other people who are involved in their implementation, about the social model of disability and about the benefits of direct payments and individual budgets for disabled people (Thompson, 2001; Oliver and Sapey, 2006).

Finally, it was argued that service commissioners have an important role to play in commissioning services which enable disabled people to live independently and which are cost effective. The CSCI (2006) revealed that service commissioners' support for direct payments and other more modern forms of personalised support was increasing but that this was occurring slowly. Disabled people (Barnes and Mercer, 2006) clearly feel that the current commissioning system is putting user-controlled organisations at a disadvantage and that

service commissioners need to do more to support these types of organisations. Service commissioners should address these concerns in the type of commissioning strategies being proposed by the CSCI (2006).

Bibliography

Audit Commission (1992) <u>Community Care: managing the cascade of change</u>, London: Audit Commission.

Barnes, C. (1991a) <u>Disabled People in Britain and Discrimination: A case for anti-</u> discrimination legislation, London: Hurst.

Barnes, C. (1991b) "Chapter 6: The Health and Social Support Systems", in Barnes. C, <u>Disabled People in Britain and Discrimination: A case for anti-</u> <u>discrimination legislation</u>. Available from: <u>www.leeds.ac.uk/disability-</u> <u>studies/archiveuk/index</u> (accessed on 01/06/07).

Barnes, C. (1991c) "Chapter 5: The Disability Benefits System", in Barnes. C, <u>Disabled People in Britain and Discrimination: A case for anti-discrimination</u> <u>legislation</u>. Available from: <u>www.leeds.ac.uk/disability-studies/archiveuk/index</u> (accessed on 01/08/07).

Barnes, C. (2005) "Independent Living, Politics and Policy in the United Kingdom: A Social Model Account", <u>Review of Disability Studies</u>, 1 (4), pp. 5-13.

Barnes, C. and Mercer, G. (2006) <u>Independent Futures: Creating user-led</u> <u>disability services in a disabling society</u>, Bristol: The Policy Press. Beresford, P. (2007) <u>The Changing Roles and Tasks of Social Work from Service</u> <u>Users' Perspectives: a literature informed discussion paper</u>. Available from: <u>http://www.gscc.org.uk/NR/rdonlyres/072DD7D6-B915-4F41-B54B-</u> <u>79C62FDB9D95/0/SoLSULiteraturereviewreportMarch07.pdf</u> (accessed on 25/06/07).

Blewett, J., Lewis, J. and Tunstill, J. (2007) <u>The Changing Roles and Tasks of</u> <u>Social Work: a literature informed discussion paper</u>, London: Synergy Research and Consulting. Available from: <u>http://www.gscc.org.uk/NR/rdonlyres/8BE06845-</u> <u>9895-465B-98C2-31CF227D7422/0/SWrolestasks.pdf</u> (accessed on 25/06/07).

Brand, D., Reith, T. and Statham, D. (2005) Core roles and tasks of social workers. A scoping study for the GSCC, London: General Social Care Council.

Brisenden, S. (1989) A Charter for Personal Care, <u>Progress</u>, 16, Disablement Income Group.

Campbell, J. and Oliver, M. (1996) <u>Disability Politics: Understanding our Past,</u> <u>Changing our Future</u>, London: Routledge.

Clements, L. (2004) <u>Community Care and the Law</u>, London: Legal Action Group Education and Service Trust Limited. CSCI (Commission for Social Care Inspection) (2004) <u>Direct Payments. What are</u> the Barriers? London: CSCI. Available from:

http://www.csci.org.uk/PDF/direct_payments.pdf (accessed on 23/05/07).

CSCI (2006) <u>The state of social care in England 2005-06</u>, London: CSCI. Available from: <u>http://www.csci.org.uk</u> (accessed on 20/06/07).

DH (Department of Health), Department of Social Security, Welsh Office, Scottish Office (1989) <u>Caring for People: Community Care in the Next Decade</u> and Beyond, London: HMSO Cm849 (White Paper).

DH, Department of Social Security, Welsh Office, Scottish Office (1990) <u>Community Care in the Next Decade and Beyond: Policy Guidance</u>, London: HMSO.

DH, Social Services Inspectorate, Scottish Office, Social Work Services Group (1991a) Care Management and Assessment: manager's guide, London: HMSO.

DH, Social Services Inspectorate, Scottish Office, Social Work Services Group (1991b) <u>Care Management and Assessment: Practitioner's Guide</u>, London: HMSO.

DH/Scottish Office/Welsh Office/Northern Ireland Office (1996) Community Care (Direct Payments) Bill: Consultation Paper, London: DH.

DH (1996) <u>Community Care (Direct Payments) Act 1996</u>, London: HMSO. Available from: <u>http://www.opsi.gov.uk/acts/acts1996/1996030.htm</u> (accessed on 16/05/07).

DH (1998) Modernising Social Services: Promoting Independence, Improving Protection, Raising Standards, London: Department of Health.

DH (2000) <u>No Secrets: Guidance on Developing and Implementing Multi-Agency</u> <u>Policies and Procedures to Protect Vulnerable Adults</u>, London: The Stationery Office.

DH (2001) <u>Valuing People: a new strategy for learning disability for the 21st</u> <u>century</u>, London: HMSO.

DH (2002) Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care, LAC(2002)13, London: Department of Health.

DH (2003a) <u>Direct Payments Guidance: Community Care, Services for Carers</u> and Children's Services (Direct Payments) Guidance England 2003, London: Department of Health. DH (2003b) <u>Fairer Charging Policies for Home Care and other non-residential</u> <u>Social Services: Guidance for Councils with Social Services Responsibilities</u>, London: Department of Health.

DH (2005) Independence, Well-being and Choice: Our vision for the future of social care for adults in England, London: The Stationery Office.

DH (2006) Our Health, Our Care, Our Say: a new direction for community

services, London: The Stationery Office. Available from:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicy AndGuidance/DH_4127453 (accessed on 16/05/07).

DH (2007a) Individual Budgets, Available from:

http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Socialcar e/DH_4125774 (accessed on 16/05/07).

DH (2007b) Individual Budgets Pilot Newsletter March 2007, Available from: http://www.individualbudgets.csip.org.uk (accessed on 16/06/07).

DH (2007c) <u>Care Services Efficiency Delivery</u>. Available from: <u>http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/DH_4089</u> <u>166.pdf</u> (accessed on 20/06/07). DH (2007d) <u>Modernising Adult Social Care – what's working</u>, London: Department of Health.

DH (2007e) <u>Commissioning framework for health and well-being</u>, London: Department of Health.

DH and DfES (Department for Education and Skills) (2006) <u>Options for</u> <u>excellence: Building the social care workforce of the future</u>, London: The Stationery Office.

DRC (Disability Rights Commission) (2006) Disability Briefing, London: DRC.

Ellis, K. (2007) "Direct Payments and Social Work Practice: The Significance of "Street-Level Bureaucracy" in Determining Eligibility", <u>British Journal of Social</u> <u>Work Advance Access</u>, 1 of 18.

Gershon, P. (2004) <u>Releasing resources to the front line: Independent Review of</u> <u>Public Sector Efficiency</u>, London: HMSO. Available from: <u>http://www.hm-</u> <u>treasury.gov.uk/media/879E2/efficiency_review120704.pdf</u> (accessed on 20/06/07). Gillman, M. (2004) "Diagnosis and Assessment in the Lives of Disabled People: Creating Potentials/Limiting Possibilities", in Swain, J., French, S., Barnes, C. and Thomas, C. (Eds.) <u>Disabling Barriers – Enabling Environments (2nd Edition)</u>, London: Sage Publications Ltd.

Glasby, J. and Littlechild, R. (2002) <u>Social Work and Direct Payments</u>, Bristol: The Policy Press.

Gray, A., Whelan, A. and Norman, C. (1988) <u>Care in the Community: a Study of</u> <u>Services and Costs in Six Districts</u>, University of York: Health Economics Consortium.

Griffiths, R. (1988) <u>Community Care: Agenda for Action: a report to the Secretary</u> of State for Social Services, London: HMSO.

Henwood, M. and Hudson, B. (2007) <u>Review of the Independent Living Funds</u>. Available from: <u>http://www.ilf.org.uk/cms_media/files/full_ilf_report.pdf</u> (accessed on 25/06/07).

Holloway, M. and Lymberry, M. (2007) "Editorial – Caring for People: Social Work with Adults in the Next Decade and Beyond", <u>British Journal of Social Work</u>, 37, pp. 375-386.

HMSO (2003) <u>Statutory Instrument 2003 No. 762 – The Community Care,</u> <u>Services for Carers and Children's Services (Direct Payments) (England)</u> <u>Regulations 2003,</u> London: The Stationery Office. Available from: <u>http://www.opsi.gov.uk/si/si2003/20030762.htm</u> (accessed on 16/05/07).

HM Treasury (2006) <u>Long-term opportunities and challenges for the UK: analysis</u> for the 2007 Comprehensive Spending Review, London: HMSO. Available from: <u>http://www.hm-treasury.gov.uk</u> (accessed on 27/06/07).

Hudson, B. (1993) "The Icarus effect", <u>Health Service Journal</u>, 18 November, pp. 27-29.

Hunt, P (Ed.). (1966) <u>Stigma: The Experience of Disability</u>, London: Geoffrey Chapman.

Hurstfield, J., Parashar, U. and Schofield, K. (2007) <u>The cost and benefits of</u> <u>independent living</u>, London: Office for Disability Issues. Available from: <u>http://www.officefordisability.gov.uk/docs/independent_living_report.pdf</u> (Accessed on 04/07/07).

Ibsen (2007) Individual Budgets Evaluation: A Summary of Early Findings, Available from: <u>http://www.york.ac.uk/inst/spru/pubs/rworks/IbsenSummary.pdf</u> (accessed on 03/08/07). ILF (Independent Living Fund) (2000) <u>Guidance notes for the 93 Fund and</u> <u>Extension Fund</u>, Nottingham: Independent Living Fund.

Jones, C. (2002) "Poverty and Social Exclusion", in Davies, M. <u>The Blackwell</u> <u>Companion to Social Work</u>, Oxford: Blackwell Publishing Ltd.

Kestenbaum, A. (1993a) <u>Cash for care: A report on the experience of</u> <u>Independent Living Fund Clients (2nd Edition)</u>, London: RADAR/Disablement Income Group.

Kestenbaum, A. (1993b) <u>Making community care a reality: The Independent</u> <u>Living Fund, 1988-1993</u>, London, RADAR.

Leece, J. and Bornat, J. (Eds.) (2006) <u>Developments in Direct Payments</u>, Bristol: The Policy Press.

LGA (Local Government Association) (2006) <u>Social Services finance 2005-06: a</u> <u>survey of local authorities</u>, London: LGA Publications. Available from: <u>http://www.lga.gov.uk</u> (accessed on 20/06/07)

Lomas, A. (2006) "Care managers and direct payments", in Leece, J. and Bornat, J. (Eds.) <u>Developments in Direct Payments</u>, Bristol: The Policy Press.

McDonald, A. (2006) <u>Understanding Community Care: A Guide for Social</u> Workers (2nd Edition), Basingstoke: Palgrave Macmillan.

Miller, E.J. and Gwynne, G. V. (1972) <u>A Life Apart</u>, London: Tavistock.

Morris, J. (1993) Independent Lives: Community Care and Disabled People, Basingstoke: Macmillan Press Ltd.

Morris, J. (1995) "How to get money to pay for personal assistance and have control over how it is spent", in BCODP (ed.) <u>Controlling your own personal</u> <u>assistance services</u>, Available from:

http://www.independentliving.org/ENILBCODPPaySchemes.html.

Morris, J. (2005) <u>Independent Living: The role of evidence and ideology in the</u> <u>development of government policy</u>, (Paper delivered at the Cash and Care Conference, Social Policy Research Unit, University of York, 12-13 April 2005), Leeds: Disability Studies Archive. Available from: <u>www.leeds.ac.uk/disability-</u> <u>studies/archiveuk/index</u> (Accessed on 01/06/07).

NHS (2007) <u>Community Care Statistics 2005-2006: Referrals, Assessments and</u> <u>Packages of Care for Adults, England</u>, The Information Centre. Available from: http://www.ic.nhs.uk/webfiles/publications/repcssr06/RAPnationalreport.pdf (accessed on 29/05/07).

Oliver, M. (Date unknown) <u>Capitalism, Disability and Ideology: A Materialist</u> <u>Critique of the Normalization Principle</u>. Available from:

http://www.leeds.ac.uk/disability-studies/archiveuk/index (accessed on 28/06/07).

Oliver, M. (1983) Social Work with Disabled People, Basingtoke: Macmillan.

Oliver, M. (1990) The Politics of Disablement, Basingstoke: Macmillan.

Oliver, M. and Sapey, B. (2006) <u>Social Work with Disabled People (3rd Edition)</u>: Basingstoke: Palgrave Macmillan.

PMSU (Prime Minister's Strategy Unit) (2005) <u>Improving the Life Chances of</u> <u>Disabled People: Final Report</u>, London: PMSU.

Poll, C., Duffy, S., Hatton, C., Sanderson, H. and Routledge, M. (2006) <u>A report</u> on in Control's first phase 2003-2005, London: in Control Publications. Available from: <u>http://www.in-control.org.uk</u> (accessed on 16/06/07).

Priestley, M. (1999) <u>Disability Politics and Community Care</u>, London: Jessica Kingsley Publishers.

Priestley, M. (2004) Tragedy Strikes Again! Why Community Care still Poses a Problem for Integrated Living, in Barnes, C., French, S., Swain, J., & Thomas, C <u>Disabling Barriers – Enabling Environments</u>, London: SAGE Publications Ltd.

Riddell, S., Priestley, M., Pearson, C., Mercer, G., Barnes, C., Jolly, D. and Williams, V. (2006) <u>ESRC End of Award Report (RES-000-23-0263) Disabled</u> <u>People and Direct Payments: A UK Comparative Study</u>. Available from: <u>http://www.leeds.ac.uk/disability-studies/projects/ukdirectpayments.htm</u> (accessed on 23/05/07).

SCIE (Social Care Institute for Excellence) (2005) <u>Adult Services Resource</u> <u>Guide 5: Direct payments: answering frequently asked questions</u>, London: SCIE. Available from:

http://www.scie.org.uk/publications/resourceguides/rg05/files/rg05.pdf (accessed on 16/05/07).

SCIE (2007) <u>Research Briefing 20: Choice, control and individual budgets:</u> emerging themes, London: SCIE. Available from:

http://www.scie.org.uk/publications/briefings/files/Scare_20.pdf (accessed on 16/05/07).

Stainton, T. and Boyce, S. (2004) ""I have got my life back": user's experiences of direct payments", <u>Disability and Society</u>, 19 (5), pp. 443-454.

Stone, D. (1985) The Disabled State, Basingtoke: Macmillan.

Swain, J., French, S., Barnes, C. and Thomas, C. (Eds.) (2004) <u>Disabling</u> <u>Barriers – Enabling Environments (2nd Edition)</u>, London: Sage Publications Ltd.

Thompson, P., Lavery, M. and Curtice, J. (1990) <u>Short Changed by Disability</u>, London: The Disablement Income Group.

Thompson, N. (2001) <u>Anti-Discriminatory Practice</u> (3rd Edition), Basingstoke: Palgrave.

Topss (2004) <u>The National Occupational Standards for Social Work</u>, Leeds: Topss England. Available from:

http://www.topss.org.uk/uk_eng/standards/cdrom/England/Main.htm (accessed on 22/05/07).

Ungerson, C. (1997) "Give Them the Money: Is Cash a Route to Empowerment?", <u>Social Policy and Administration</u>, 31 (1), pp. 45-53.

UPIAS (Union of the Physically Impaired Against Segregation) (1976) <u>Fundamental Principles of Disability</u>, London: UPIAS.

Wanless, D. (2006) <u>Wanless Social Care Review – Securing Good Care for</u> <u>Older People: Taking a long-term view</u>, London: King's Fund. Available from: <u>http://www.kingsfund.org.uk/publications</u> (accessed on 20/06/07).

WHO (World Health Organization) (1980) International Classification of Impairments, Disabilities and Handicaps, Geneva: WHO.

Zarb, G. and Nadash, P. (1994) <u>Cashing in on independence: Comparing the</u> <u>costs and benefits of cash and services</u>, London: BCODP.

Zarb, G. (2003) <u>Why We Need a Legal Right to Independent Living: Keynote</u> <u>paper presented at European Congress on Independent Living, Arona, Tenerife,</u> <u>24th to 26th April 2003</u>. Available from: <u>http://www.leeds.ac.uk/disability-</u> <u>studies/archiveuk/index (accessed on 28/06/07).</u>